

# Heart Failure

## Conversations about the illness trajectory

A guide ahead of your appointment at the health care center or the hospital

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## **Introduction**

Many heart failure patients and their family members have questions about the illness trajectory and the future. In this booklet you will find examples of other patients' and family member's questions about the future and what it is like to live with heart failure. The booklet can be used as a guide ahead of a conversation with health care professionals and you can choose the questions that apply to your situation.

You probably also want to ask questions about self-care, medication, physical activity, etc. However, this booklet only focuses on questions about the future and the trajectory of heart failure.

In the booklet you can tick the boxes for the questions you would like to discuss. You can also make a note of questions you would like to discuss that are not included in the list.



## Heart Failure and its impact on daily life

*Tick the boxes for the questions you want to discuss*

- 1. What is heart failure?
- 2. Is heart failure a serious illness?
- 3. Is heart failure a lifelong illness?
- 4. What is the likely impact of heart failure on my future?
- 5. What can I do to improve my prognosis and my condition?
- 6. What goals are realistic for the future?

Other questions:

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## Help, support and treatment

*Tick the boxes for the questions you want to discuss*

- 7. What symptoms might I experience if my condition deteriorates in the future, and what should I do if they occur?
- 8. What support and treatment are available to me if my illness deteriorates?
- 9. Who can I talk to about things that worry or bother me?
- 10. Who can my family talk to about things that worry or bother them?
- 11. Can I choose where to be cared for, if I deteriorate?
- 12. Can I be cared for at home, if I deteriorate?
- 13. What support is available to me if I choose to be cared for at home?
- 14. Who can help me to decide about my care?
- 15. Who will be responsible for my care if I deteriorate?

Other questions:

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# End-of-life

The questions below might not apply to your current situation. You do not need to read them if you do not want to, but you might want to discuss them in the future.

*Tick the boxes for the questions you want to discuss*

- 16. How will I know if I am approaching the end-of-life?
- 17. What will happen to my heart failure treatment at the end-of-life?
- 18. Living with heart failure, how will the end-of-life be?
- 19. How will the last days in my life be, dying from heart failure, is there much suffering with for example breathing problems and anxiety?

Own questions:

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## Other questions that family members may want to discuss

*Tick the boxes for the questions you want to discuss*

- 20. Are there things the person who is ill should avoid doing?
- 21. How do I best help my family member with heart failure if he/she deteriorates?
- 22. If needed, how do I get help to look after my family member with heart failure?
- 23. Who can I talk to about things that worry or bother me about the care given to my family member with heart failure?

The questions below might not apply to your current situation. You do not need to read them if you do not want to, but you might want to discuss them in the future.

- 24. What support is there for me if my family member's heart failure deteriorates, and I feel that I cannot do anymore?
- 25. How do I know that the end-of-life is approaching??
- 26. How will my family member with heart failure react when the illness deteriorates?
- 27. How will family members react when the family member with heart failure deteriorates?
- 28. How do I know that my family member with heart failure has passed away?

Other questions:

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**Other questions for you who has a heart failure pacemaker or an implantable cardioverter defibrillator**

*Tick the boxes for the questions you want to discuss*

- 29. What will happen to my ICD/CRT/pacemaker treatment at the end-of-life?
- 30. What impact will my heart failure pacemaker (CRT), pacemaker or implantable cardioverter defibrillator (ICD) have on my last days of life?
- 31. How will the shocks in my ICD be switched off?
- 32. What will happen to my heart if my ICD is switched off?
- 33. Can the shocks in my ICD be switched off without mine or my family members' knowledge?

Other questions:

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